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Clinical Proceedings

CHILDREN'S HOSPITAL WASHINGTON, D.C.

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The Mongoloid Newborn: Problems Faced by the Pediatrician and Family

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NICHOLAS P. HARITOS, M.D.†

The handling of mongoloid newborns from the total family aspect is usually not stressed in a pediatric residency program. It is the authors' impression that this area of pediatric practice represents a difficult one, especially in the physician-parent relationship. The purpose of this survey was to determine how the practicing pediatrician in the Washington, D. C. area handles the mongoloid newborn. The results of this study were not intended to be of statistical significance. Questionnaires were sent to 50 attending physicians of the Children's Hospital and 35 questionnaires were returned. These replies together with a brief review of the literature on the newborn mongoloid form the basis of this report.

The incidence of mongolism in the newborn in the United States is approximately 1 in every 500 to 700 births. Jenkins[1] found 6 Mongols among 3,818 babies born alive (1 in 636) at the Presbyterian Hospital in Chicago. Beidleman[2] found 48 newborn mongoloids among 14,000 babies born alive (1 in 292) at the Boston Lying-in Hospital, while Parker[3] found 32 Mongols among 27,931 live born babies (1 in 873) at the Gallinger Municipal Hospital, Washington, D. C. Although the over-all incidence is not great, the importance of mongolism lies in the fact that it constitutes one of the largest groups of mentally retarded patients requiring institutionalization, and is the largest group in which a diagnosis of mental retardation can be made at birth. The diagnosis of mongolism in the newborn by a pediatrician has so many overtones far beyond the description of a clinical entity. The problems presented by the birth of

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a mongoloid infant are many and of deep concern to the baby, his family and his pediatrician.

The distinguishing characteristics of mongolism in the newborn infant are, as a rule, quite obvious. The eyes have an upward and outward slant which is often accentuated by the presence of an epicanthal fold. The palpebral fissure is short and often narrow, the nasal bridge is low, and the cheekbones high. The skull is small and flattened anteriorly and posteriorly. The neck is shortened and there is laxity of the skin at the lateral aspects of the neck. The mouth appears small, the lips are thin, the tongue tends to protrude, and a highly arched palate is usually present. The hands tend to be broad and thick, the thumbs stubby and flat, and the little fingers short and curved inward. A single transverse palmar crease is usually present instead of the two creases normally seen. The feet are often broad and stubby also, and the great toe may be widely separated from the other toes, giving a thumblike appearance. Muscular hypotonicity is observed in nearly all cases. A weak Moro reflex is usually present. In both males and females, the external genitals tend to be small. A congenital heart defect is present in a relatively high percentage of these infants.

The questionnaire used in this study is presented in figure 1. Not all the questions asked were answered by all those physicians returning their questionnaires, and more than one answer was given for each question in many instances.

I. *The number of mongoloid newborns seen:* The range of answers to this question was from 1 to over 200 patients.

II. *The establishment of the diagnosis of mongolism in the newborn:* Of the 35 physicians answering this question, fourteen established the diagnosis on the basis of their own evaluation, and twenty-one used a consultant to help confirm it. Another pediatrician was used most frequently by those requesting consultation (20 physicians); two physicians used a neurologist. No other consultant was mentioned.

III. *Management of the "doubtful" diagnosis:* Thirty physicians used other consultants in addition to their own evaluation if the diagnosis was doubtful. Seven physicians suggested the possibility of mongolism to the parents immediately, while seventeen preferred to observe the infant for a period of time before mentioning the diagnosis.

IV. *Time of informing the parents of the diagnosis:* Twenty-seven physicians informed the mongoloid child's parents of the diagnosis while the mother and infant were still in the hospital; seven physicians preferred to wait, but all of these told the parents within the first six months of life.

V. *Relative first informed of the diagnosis:* Two physicians usually first

1. How many mongoloid newborns have you seen
   a) in your practice?
   b) as a consultant?
2. How do you establish the diagnosis of mongolism in the newborn in the "typical" case?
   a) on the basis of your evaluation alone?
   b) by the use of consultants in addition to your own evaluation?
   c) If b), consultants are:
      (1) pediatricians
      (2) neurologists
      (3) other
3. If the diagnosis is doubtful, do you
   a) have other consultants in addition to your own evaluation?
   b) suggest the possibility of mongolism to the parents?
   c) prefer to observe the infant without mentioning the possible diagnosis to the parents?
4. When do you inform the parents of the diagnosis?
   a) immediately (i.e., while mother and infant are still in the hospital)
   b) after discharge from the hospital
   c) if b), when?
5. Do you present the diagnosis to:
   a) mother first?
   b) father first?
   c) if b), do you ask him to give the diagnosis to the mother?
   d) both at the same time?
   e) other (grandparents, etc.)?
6. Have there been circumstances under which you have not given the diagnosis to the parents immediately after the diagnosis was made?
   a) no
   b) yes
   c) if b), please list the circumstances
7. Have any parents been unable to accept your diagnosis of mongolism in their child?
   a) no
   b) yes
   c) if b), how do you handle the situation?
8. After you give the diagnosis of mongolism to the parents, do you advise:
   a) immediate institutionalization (i.e., as soon as is practically possible)?
   b) keeping the newborn at home until the parents request institutionalization?
   c) keeping the infant home indefinitely?
   d) other?
9. If you advised institutionalization, how many parents have refused this advice?
10. In the instances where the mongoloid newborn was kept at home, approximately what percentage of these families do you consider as being "well adjusted" in relation to the infant?
11. When parents ask about further pregnancies, what do you advise and what criteria do you use in determining your answer?
12. What question does the family most frequently ask upon being presented with the diagnosis of mongolism in their newborn?
13. What do you as a physician consider the most difficult aspect of handling the mongoloid infant and his family?

FIG. 1. Questionnaire used in this survey.

inform the mother that her child is mongoloid, twenty-two inform the father first (one physician asks the father to inform the mother; sixteen inform her themselves), while 10 physicians inform both parents at the same time. In no instance did any physician inform other relatives first.

VI. *Circumstances in which informing the parent of the diagnosis was delayed:* Twenty physicians had never found it necessary to delay presentation of the diagnosis; 11 physicians had on one or more occasions preferred to delay. In four instances, the reason given was illness in the mother; in one, illness in the father; in one, illness in the infant; in three, "emotional" parents; in two, birth of a first boy or girl after the birth of a child of the opposite sex; and in one instance, unavailability of the father (at sea with the Navy). One physician stated that he once delayed presenting the diagnosis because of illness in the father, but the reaction at the time the diagnosis was presented was so great that he would never again delay in presenting the diagnosis.

VII. *Inability of parents to accept a diagnosis of mongolism:* Fifteen physicians denied ever having trouble with parents accepting a diagnosis of mongolism; on the other hand, twenty reported having this difficulty. Thirteen of the latter group met the problem by suggesting consultation with another physician to be chosen by either himself or the parents; six said they allowed the passage of time to make the diagnosis certain to the parents themselves; and three physicians reported using "orientation, discussion, and counseling." Three physicians reported that presenting the parents with a diagnosis of mongolism resulted in the parents leaving them for other physicians.

VIII. *Advice given parents after a diagnosis of mongolism has been made:* Seven physicians reported that they usually recommended immediate institutionalization while fifteen recommended keeping the infant at home until the parents felt it necessary to institutionalize him; two physicians recommended keeping the infant home indefinitely. Three physicians made no recommendation to the parents but "laid the cards on the table" and allowed the parents to make the decision of whether or not to institutionalize the infant. Qualifications for recommending immediate institutionalization included an emotionally unstable mother and/or father, the presence of older, normal children, and a request for immediate placement by the parents. Qualified answers for keeping the infant at home included if there were no other children in the family and until siblings and relatives became concerned over this "difficult child."

IX. *Parents' refusal of recommendation of immediate institutionalization:* The number of parents in a given physician's practice who rejected a recommendation of institutionalization varied widely; some physicians reported that all the parents rejected such a recommendation while others reported general acceptance.

X. *Physicians' estimate of percentage of well adjusted families with a mongoloid infant in the home:* The answers again varied widely, with a preponderance of physicians feeling that the newborn mongoloid infant was not an upsetting factor in the home.

Percentage of well adjusted families	*Number of Physicians*
0–25%	9
26–50%	2
51–75%	4
76–100%	17

XI. *Physicians' advice to parents concerning further pregnancies:* Twenty-two physicians advised the parents to have further pregnancies, using as their criterion the low incidence of recurrence. The parents were particularly advised to have further children if there were no other children in the family and if the parents were young; two physicians advised against further pregnancy, particularly if there were other normal children in the family and the parents were older. Five physicians stated they preferred to present the known facts concerning the possibility of recurrence to the parents and allowing them to come to their own decision. One physician referred the parents to a genetic clinic.

XII. *Most frequent questions asked the physician by the parents of a mongoloid newborn following presentation of the diagnosis:* The following questions asked by the parents are presented in an order of decreasing frequency with which they were asked:

A. Prognosis
   1. Will he be mentally retarded?
   2. What is the highest mental level we can expect?
   3. Will he live?
   4. How much motor retardation will there be?
   5. Are all cases equally severely affected?
   6. Can he marry?
   7. Can he go to school?
   8. Will he outgrow it?
   9. Will he be able to take care of himself?
   10. How soon can we determine the level of retardation?
   11. Will he be a problem in sexual license?

B. Etiology
   1. Why is he mongoloid?
   2. Is it hereditary?
   3. What caused it?
   4. What did we do to cause it?
   5. What is mongolism?

C. Care of the infant
   1. How can we care for the baby?
   2. What shall we do?
   3. Is there any treatment?
   4. How much trouble will he cause the family?

D. Physician's certainty of the diagnosis
E. Recurrence in future pregnancies
F. Miscellaneous
   1. Why did it happen to us?
   2. What shall we tell the other children and our friends?
   3. What effect will there be on the other children?

It appears that approximately 50 per cent of the parents are concerned with the future abilities of their infants. Other feelings that are reflected by the questions are those of guilt and social stigmata.

XIII. *Physicians' opinion of the most difficult aspect of handling the mongoloid infant and his family:* The answers are again listed in the order of decreasing frequency.

1. The handling of the other normal children in the family.
2. Proper placement of the mongoloid infant.
3. Acceptance of the family of the permanent retardation.
4. Presenting the diagnosis to the parents.
5. Following the family through the period of adjustment.
6. Alleviating the feeling of guilt in the parents.
7. Acceptance of the diagnosis by the parents.
8. Answering questions relevant to the problem.
9. My own feeling of pity towards the parents.
10. Estimating the future mental potential of the infant.
11. Social stigmata for the family.
12. What to do about the question of future pregnancies.
13. Separation of the newborn from the family before they become too attached to him.
14. Frequent infections in the mongoloid infant.

DISCUSSION

The following section is an attempt by the authors, via a literature review, to discover what is known of mongolism and, by exploring the beliefs of authorities in the field, to arrive at a satisfactory approach toward the diagnosis and management of this severely handicapping condition.

Diagnosis. The diagnosis of mongolism in the newborn period is made from the presence of certain stigmata of the syndrome previously described. By no means are all of them present in each case.[4] Yannet[5] states that 70 to 90 per cent of all cases of mongolism should be definitely established during the neonatal period, the percentage depending on the experience of the physician. He considers the one pathognomonic sign in mongolism in the newborn to be the peculiar maldevelopment of the skull (particularly of the basilar bones) as expressed by the typical facies and orbital slant. Benda[6] concludes that the most reliable indication of the diagnosis is the general hypotonia or flabbiness of the newborn. He stresses that if a suspected mongoloid newborn is carefully examined, the most characteristic anomalies are found in the area of head development.

The difficulties concerned with the diagnosis of mongolism in the newborn period have been discussed by Øster[7] who collected a series of 65 newborns from the University Hospital in Copenhagen in whom the diagnosis of mongolism was made at birth or later. He found that in 14 of these 65 newborns the diagnosis was erroneous or had been missed. Carter and MacCarthy[8] believe that mongolism in the newborn is more often missed than erroneously diagnosed.

Cummins, Talley and Platou[9] point out that the diagnosis may be facilitated by a study of palmar dermatoglyphics. They compared clinical and dermatoglyphic diagnoses in 270 individuals and found that the characteristic changes ranked high (85 per cent) among the various stigmata of mongolism. Palmar dermatoglyphics are helpful in establishing an early diagnosis but are not diagnostic alone.

Yannet[5] states that if there is any doubt concerning the diagnosis of mongolism in the newborn he would strongly advise delaying a final diagnosis as long as possible. He stresses that the harm done by a false positive diagnosis or any implication in this direction greatly outweighs the reverse situation.

Management. Parmelee[10] states that the parents should be told that their infant is mongoloid as soon as the physician is sure of the diagnosis. Three reasons for doing so are: "First, it is the parents' right to know what the physician knows about their baby. Second, it is unfair for the physician to be obliged to carry in secrecy and alone a burden that rightfully should be shared by the parents. And third, early knowledge of the problem they face is of the greatest importance to the parents in their acceptance of, and adjustment to, their responsibilities, and in their success in working out an intelligent solution to their problem."

Kirman,[11] however, states that although the diagnosis may be made at birth, he considers that there is no virtue in telling the parents immediately. He believes that it is better if the parents are allowed to become gradually accustomed to the fact that their baby is abnormal.

Franklin[12] states that to tell the father in the neonatal period that his newborn is mongoloid with an injunction not to tell his wife is to place a great strain on him and should not be done.

It has been suggested by some authors[13-15] that if the diagnosis of mongolism can be made at birth the infant should be separated from the family at that time. Hill[14] advises separation from the family at this time because he feels that it becomes more difficult for the parents to break off attachment to the baby later. Bakwin and Bakwin[16] state that the question of institutional care must be decided individually. They feel that most mongoloid newborns are better cared for in an institution especially when the parents are young and have other children or plan to have more. Evans and Carter[17] warn the physician who recommends

institutionalization of the mongoloid newborn to first find out if any vacancies exist in available institutions. Otherwise, if the parents accept his advice only to find no vacancies, psychological conflict may arise because of being unable to follow the physician's advice.

The desirability of the noninstitutionalization of the newborn mongoloid has recently been stressed.[18-22] Yannet[5] states that most parents with suitable indoctrination and orientation will succeed in meeting in a satisfactory manner the emotional impact of a mongoloid child in the family. Esty[18] states that separation of a mother from her mentally subnormal newborn infant does not necessarily prevent or remedy the emotional impact of the event. Many authors[11,18,19,22] have expressed their feeling that the mongoloid infant profits from the mother-child relationship in the first few years of life and does not seriously interfere with the normal emotional development of older or younger siblings. Furthermore, Beddie and Osmond[23] have pointed to the possible serious psychological consequences to the mother of a separation from her newborn infant at the time of delivery.

Franklin[12] states that the parents should be given a description of the life history of the mongoloid baby before a decision regarding institutionalization is made. Parents who lack accurate medical knowledge of mongolism often imagine what they do not know, and this picture may be frightening. Parmelee[10] believes that only the parents should make the decision concerning institutionalization of their newborn. Yannet[5] states that most homes are suitable for the care and training of the mongoloid child during infancy and early childhood but few continue to be so beyond this period.

Jolly[22] recommends that the mother take the newborn mongoloid home so that she can see for herself that the newborn is not normal and may need the special facilities of an institution. He believes that the physician should keep the need for eventual institutionalization active in the thinking of the parents. Furthermore, he believes that "there is a best time in every case at which the separation can be brought about with the least emotional damage to both the family and the retarded child" and the physician should be able to recognize this optimum time when it presents itself.

Bowlby[24] has clearly demonstrated that "when deprived of maternal care, the child's development is almost always retarded—physically, intellectually, and socially." Quaytman[21] compared institutionalized infants with mongolism with those seen at clinic and found significantly higher mental and social ages in the clinic group.

One can conclude that generalizations regarding the advantages of institutional care for the mongoloid newborn cannot be made. Each

family constitutes a separate problem. Many factors must be taken into consideration. Among these are the attitude of the parents toward the newborn, the social background of the family, the presence of siblings, the economic status of the family, and the availability of satisfactory institutions.

Almost every mother who has had a mongoloid infant and who wants more children will consult her physician as to whether or not there is any possibility that she may have another mongoloid child. According to the experience of most authors the occurrence of more than one mongoloid in a family is extremely rare. Warner,[25] in a review of the literature, found only 48 families in which mongolism occurred more than once among siblings. Øster[26] found that the risk of a mother having another mongoloid child was not significantly greater than the risk for other women in the same age group.

Etiology. Jervis[27] states that the medical literature is "rich in hypotheses, and poor in detailed factual data." Warkany[28] has recently collected a list of 39 theories proposed in the literature to explain the etiology of mongolism. He divided these theories into four main groups: 1) reversion to a primitive ancestral type; 2) a genetic origin involving one or more genes, mutations, injury to germ cells, or interaction of the embryonic genetic constitution with uterine conditions; 3) disturbances in environment, including accidents during gestation, disease states, aging of the mother, or aging of the ovum; and 4) changes within the child, especially endocrine deficiencies.

One fact appears to be fairly well established, that the frequency of mongolism increases with advancing maternal age. Penrose[29] has shown that 40 per cent of mongoloid children are born after the mother has reached the age of 40 years. Bleyer[30] plotted the ages of 2,822 mothers who gave birth to mongoloid infants during the year 1934. His distribution curve showed the peak age of all mothers delivering babies in the United States in 1934 to be 24 years, while the peak age of mothers producing mongoloid infants was 41 years. Book and Reed[31] observed that at a maternal age of 45 years or more, the statistical chances of having a mongoloid infant is about 3.2 per cent or approximately 1 in 30.

It is now established that the normal chromosome number in humans is 46 and that mongoloid children have 47 chromosomes.[32,33] The discovery of an extra chromosome in the mongoloid will undoubtedly stimulate more research into the etiology of this entity.

Mental Status and Education. Almost all observers agree that mongoloids are always retarded mentally. Malzberg[34] studied the intelligence tests in 880 mongoloids in New York and found that 24.5 per cent were idiots, 71.6 per cent imbeciles, and 3.8 per cent morons. Quaytman[21] found in a

series of 40 mongoloid children that 5 per cent were in the idiot range (I.Q. 0 to 24), 70 per cent were in the imbecile range (I.Q. 25 to 49), 22.5 per cent were in the moron range (I.Q. 50 to 69), and 2.5 per cent were borderline (I.Q. 70 to 79). Rosenzweig[35] states that with proper care and training during infancy and childhood the mongoloid might present a much more encouraging educational picture. Benda[36] states, "In considering training facilities, mongoloid children should not be trained with other low grade mentally deficient children unless necessary, because most of the imbeciles of other types are not capable of much further progress, while the mongoloid has dormant possibilities of improvement. Mongoloids profit best in a kindly surrounding with older children of established patterns, because the mongoloid learns by association with other people."

Sexual Status. Mongoloids are generally considered to be sterile, but there are reports of a few who have borne children.[37,38]

Prognosis. Record and Smith[39] compiled a series of 252 mongoloids. They estimated that nearly two-fifths of mongoloids alive shortly after birth were dead by the end of the first month, less than half survived the first year, and only two-fifths were alive at the end of 5 years. Deaths are usually due to upper respiratory infections to which Mongols are unusually susceptible.

Treatment. At the present time there is no accepted satisfactory treatment of mongolism. Thyroid,[40] glutamic acid,[41] ephedrine,[36] gonadotrophic hormone,[36] and pituitary powder combined with small doses of thyroid extract[42] all have been tried in the therapy of mongolism; there is no agreement that any of them is significantly effective.

SUMMARY

A survey has been made to determine how the practicing pediatrician in the Washington, D. C. area handles the mongoloid newborn. The birth of a mongoloid infant presents many problems to the family and the pediatrician, many of which are not easily solved.

A brief review of the literature concerning the handling of the mongoloid newborn and mongolism has been presented.

It is hoped that the discovery of an extra chromosome in the mongoloid will stimulate more research into the etiology of this entity.

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Symposium: The Physician and Mongolism

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J. William Oberman, M.D.‡

Dr. Werkman:

This conference is an inquiry into the tact, clinical judgment and strategy which go into the handling of mongoloid children. It might be subtitled, "What can be done for and with mongoloid youngsters?" Our interest is not in the formal diagnostic aspects of mongolism nor in genetic, metabolic or hormonal studies, interesting as they are, but rather in the attempt to explore the pediatrician's views about the handling of mongoloid children and also to indicate some aspects of the public health problems in regard

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to them. It is estimated that there are between 28,000 and 30,000 mongoloid people in the United States today. In New York City 500 mongoloid births are believed to occur each year. The District of Columbia is considered to be about one tenth as large as New York City; this would add 50 mongoloid infants to our population yearly. In all these mongoloid children, the major psychological aspect is the severe retardation which is almost always present. The problems surrounding this retardation and the management of it involve both pediatrician and community in a number of ways, and also give rise to the larger philosophical problem of the impact of imperfection on the family and the community.

Dr. Washington:

The first problem in dealing with mongoloid infants may be the establishment of a diagnosis. Usually the feature which draws the condition to the physician's attention is the facial appearance. Many times this is so typical that it has been noticed in the delivery room and constitutes conclusive evidence in itself. When there is doubt about the face it is most important for the physician to have familiarized himself with other features, no one of which would be significant alone, but which in combination with the suspicious face, convert the suspicion into a certainty. I find myself reaching first for the hand. The presence of a single transverse palmar line is helpful, but in my experience a more frequent abnormality is seen in the two distal flexion lines of one or both little fingers. Very often these either are fused into a single line or are distinctly closer together than normal. The merging of these lines no doubt is secondary to the shortening of these fingers and associated with the undergrowth of the middle phalangeal bone, often demonstrable by x-ray.

Limpness is usually quite distinct, the baby feeling like a sack of salt when handled. The smallness of the head is a much neglected sign; where normal newborns have head circumferences of 13 or more inches, mongoloids measure around 12. The external ears very often are smaller and less well formed than usual. Cutis laxa at the base of the neck posteriorly may be striking. Less frequent supporting signs are separation of the big toe from its neighbor in the manner of a thumb, and congenital heart disease.

When the diagnosis is made in the nursery it is well to stay away from the mother's room until arrangements can be made to have the father and, if possible, the obstetrician present. In ordinary circumstances it is not fair to the mother to withhold the truth; on the other hand, she should not be faced with such disturbing news unsupported by her family and medical aid. Calling the obstetrician is the first move, after which the father should be contacted and informed of the true situation.

In dealing with mongolism in a newborn the pediatrician's rapport with

the family is in jeopardy. Their disappointment may be transformed in part to resentment against the source of the bad news. Certainly sympathy, straightforwardness, and lack of haste in discussing the situation will largely avoid such antagonism. It is important to explain that the parents themselves are in no way to blame. Suggestion that a consultant be called is practically always welcomed. Even when the diagnosis is in doubt, I believe parents prefer to be told. The shock of such unexpected bad news some months later is too great to be risked, and there is less harm done in facing the situation squarely from the start with parents and doctor together hoping for the best. When confirming the diagnosis in the examining room it is helpful to the parents to be called to the examining table and have pointed out the various features which lead the doctor to the unwelcome conclusion.

When should a mongoloid child be institutionalized? For some years I have recommended the postponement of this move until it is obvious to the parents that the child cannot compete happily with other children or that the well being of siblings is being interfered with. Here, I keep reassuring myself that I am not simply recommending the line of least resistance. To institutionalize a newborn is a strenuous process. Usually one or both parents are unhappy over being persuaded to abandon the baby. Finding an adequately staffed foster home is difficult if not impossible. The expense to the parents may be an unjustified burden.

Dr. Oberman:

The District of Columbia Clinic for Retarded Children is a clinic within the Bureau of Maternal and Child Health of the District of Columbia Health Department. It has been in operation since 1955 and is operated by funds from the Children's Bureau. It is, at least in part, a response to the insistence of parents of retarded children that something be done for them.

The usual retarded child is first seen in this Clinic about the age of 2½ or 3 years, because it frequently takes that length of time for both family and physician to agree that the child is retarded; occasionally, the child is seen at a younger age. The mongoloid child is the outstanding exception to that rule because he has physical stigmata which are usually recognized at birth. Consequently, a number of these children are first seen at the Clinic under the age of 1 year.

It is the Clinic's experience that most pediatricians do inform the parents at birth that their child is mongoloid. This is not universal, some physicians preferring to arrive at the diagnosis with the parents as with any other retarded child. These physicians prefer to talk over the physical abnormalities with the parents, who gradually begin asking more and more

questions until the child is about age 3 when both physician and parents decide that this child is indeed mongoloid. One would wonder if many of our medically sophisticated American parents would respond very well to this approach.

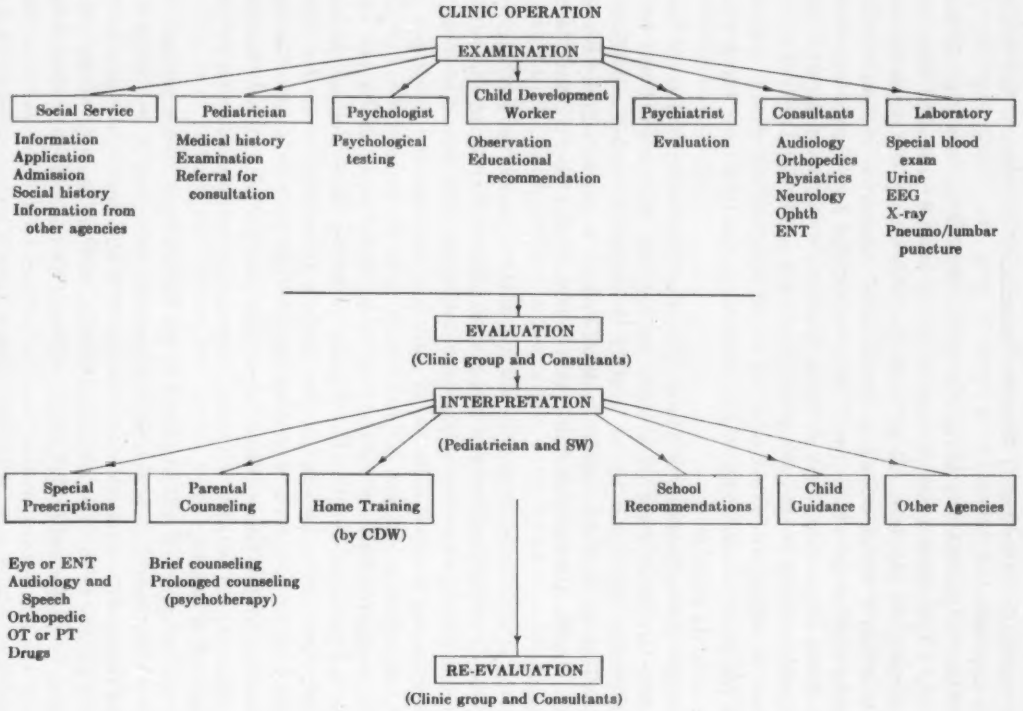
When the parents of a mongoloid child under the age of a year are seen at the Clinic, their usual reaction is one of bewilderment and hurt. Occasionally, the physician has grown horns. This usually is a physician who cannot find it within himself to sit down and adequately explain the condition, a physician who is upset by it himself and gives only a superficial rendering of an opinion. More usual, however, is the physician who does sit down and talk to the parents at some length and in quite a bit of detail. However, when parents arrive at the Clinic, they are still a little upset at the physician because, "He told us all about it, but he did not tell us what we could do about it."

Figure 1 is a diagram of Clinic operation. Routinely, preferably both parents are interviewed by a social worker; the child is examined by a pediatrician and observed by a child development worker who has a knowledge of child development and education, is psychologically tested, has a routine hearing evaluation, and is referred for further consultation as needed.

This is actually a learning experience, since a parent cannot be interviewed by all these professional people and cannot answer all their questions without getting some idea of the way they think. The parent also has a chance to see his child in action in playroom situations and sometimes to see him tested; in addition he has a chance to air his feelings as to how the child compares with normal children. It is, therefore, a rare parent who does not get some idea of what is going on during the evaluation process itself. After this very careful multidisciplinary evaluation of the child, there is an interpretation, preferably again to both parents, which is usually presented by the pediatrician. During this interpretation, which requires an hour, or even longer if necessary, everything is explored and all questions answered, if possible.

Such an approach still would not be the answer were we not prepared to say, "Your child does indeed have mongolism *but we can do this about it.*" This removes the fatalistic view that the child is doomed to an early death or inexorably to be institutionalized. Such a view particularly occurs when a poor prognosis was given at birth. Then, if for one reason or another the child was not institutionalized and the parents have a chance to see him grow, the physicians in these cases suffer quite a bit of parental enmity: "You didn't tell us that he was going to be such a nice little fellow."

At the time of the interpretation, various Clinic services may be offered: counseling to parents who are very upset, home training by the child


CLINIC OPERATION
EXAMINATION
Social Service
Pediatrician
Psychologist
Child Development Worker
Psychiatrist
Consultants
Laboratory
Information
Application
Admission
Social history
Information from other agencies
Medical history
Examination
Referral for consultation
Psychological testing
Observation
Educational recommendation
Evaluation
Audiology
Orthopedics
Physiatrics
Neurology
Ophth
ENT
Special blood exam
Urine
EEG
X-ray
Pneumo/lumbar puncture
EVALUATION
(Clinic group and Consultants)
INTERPRETATION
(Pediatrician and SW)
Special Prescriptions
Parental Counseling
Home Training
(by CDW)
School Recommendations
Child Guidance
Other Agencies
Eye or ENT
Audiology and Speech
Orthopedic
OT or PT
Drugs
Brief counseling
Prolonged counseling (psychotherapy)
RE-EVALUATION
(Clinic group and Consultants)

development worker and solid tips on how to bring up the young mongoloid child in the home (instruction in toilet training, for example), as well as other services.

Reactions to the interpretation run the gamut from acceptance to complete rejection, even following this elaborate work-up. Some parents will say, "We don't believe you, the child is not mongoloid, he isn't retarded, but can you recommend special schooling for him?" This is their way of saying that deep down they do believe it but cannot yet admit it to themselves; this is a process that sometimes takes months and years. The Clinic encourages parents to call any time about such things as developmental crises or school recommendation. At these times, we find they are more able to see and to say that their child is retarded, and they are more able to take a realistic viewpoint.

What about institutionalization? It has been estimated that four out of five pediatricians recommend institutionalization at birth. This disregards two things. First, it disregards the degree of retardation of the mongoloid child. Although the average intelligence quotient of the mongoloid child is in the 40's, it can vary from 20 to 70 in any large group. This also disregards the known good adjustment of the young retarded mongoloid child in the home. If the parents themselves are accepting of their mongoloid child, his siblings usually take over the parents' attitudes, and the siblings themselves practically never add to the problem. They are, in fact, most accepting of him and tend to overprotect him, if anything. If, however, the mongoloid child is really upsetting to his parents, their attitudes will be communicated to their normal children and problems will arise.

Should the mongoloid child be institutionalized? We believe that this is a decision the parents must arrive at themselves. In recent years, there has been a great increase in facilities for the retarded child who remains in the community, starting with nursery schools available for the retarded preschool child. For the school-aged mongoloid child there are within the public school systems "trainable" school classes for children who are severely retarded but who have some learning potential. For the older retardate, the Department of Vocational Rehabilitation is now beginning to sponsor programs for the mentally handicapped in sheltered workshop environments. Here many of these children can be trained in simple tasks, and, while they will always have to remain in a semi-protected environment, they will not be a drain on the community and will have an opportunity to develop self-respect.

What are the advantages for the mongoloid child to remain in the community? The family may eventually decide when he is 9 or 10 that he is getting a little bit too big to handle; his mother and father realize they are getting old and wonder who is going to take care of him after they have

died, etc. What has been gained? The child has been brought up in a loving family atmosphere, he has been able to make the relationships necessary to get along with other people; more concretely, he has been able to develop self-care abilities for himself, and actually adapts much more satisfactorily to an institutional setting.

The complete answer to the future of the mongoloid child and adult is not yet here and will be some time coming; we certainly look forward to what the answer will be.

Dr. Werkman:

The presentation of the newborn to parents is an extremely important event. It is the time when parents begin thinking, "All the things I didn't accomplish, all the things I couldn't do perhaps my child will do." Many parents, to a great extent mistakenly, want to live out their own fantasies and wishes through their child. Every parent eventually has the problem of accepting and living with the reality that his child may not do as well in school as he would have liked, does not have the kind of friends of whom he approves, does not fulfill the dreams of success in athletics, or music, or popularity that so many parents cherish. Life may therefore be said to be a gradual adjustment to imperfections, to disillusionment, perhaps to reality. The mongoloid infant brings home immediately a shattering of illusions which are only gradually modified in normal children in their contacts with their parents over the years. The child is an extension of the parent, and it is really the parent who is suffering a loss rather than the child.

An important recent publication by Dr. Gerhart Saenger, "The Adjustment of Severely Retarded Adults in the Community,"[1] reports a study done in New York City and answers part of the question, "What future abilities will my mongoloid child have?" This was a study of a large number of severely retarded children who had remained in the community, retarded children with IQ's less than 50. One interesting finding was that retarded children of foreign-born parents were kept in the household 80 per cent of the time, children of mixed foreign and native-born parents about 60 per cent of the time, and children of native-born parents only 40 odd per cent of the time. This effectively illustrates that there are important cultural and ethnic aspects to the problem: various groups have different ways of handling their mongoloid children.

A few parental reactions are illustrated by case vignettes. In one, the researcher asked, "What have you thought about institutionalization?" The answer was, "Well, so many people have said, 'Your life is wasted, put him away,' I hear it all the time from acquaintances. One of the neighbors has a boy who needed to be institutionalized; they were afraid he would

get into trouble so they put him in an institution. But J., he's never been that type, I wouldn't think of it." "Has anyone given you any advice against institutionalizing the child?" "The doctor who treated him at X hospital when he was younger. He said that J. wasn't the kind to be put away; he has a nice disposition; he's a good boy; he has never given me any trouble. Of course, I have had a lot of heartbreak; no one can know how much I've given up, but I'd do it again."

Another interview gives some evidence of how one mongoloid has adjusted in the adult community. She is a 20 year old who works assembling electric cord sets. "We took C. to be examined for employment at a special employment service. She assembles electric cord sets, I believe this includes cutting, assembling screws and gadgets. She is out from 9 A.M. to 4 P.M. daily; she is happy about it; she has been there for two or three years; she wouldn't take anything for going to work. The manager likes her; she has such good work habits. They think she is wonderful; she works safely and is careful; she is steady and always punctual; she gets along well with everyone there and she makes very little money, six dollars a week."

In another severely retarded male adult, 26 years old, with an IQ below 30: "This boy started working—he is now 26—when he was just a kid; he worked at the corner delicatessen for lots of years; they know there what a smart one he is; there wasn't a can in the store that he didn't know. His job now working in the dime store is for pay; they pay him 75 cents an hour and he helps pack things. He is a good boy, smart; I have got boys working for me who are dumber than he. It is not for the money that we want him to work, though; he is happier and gets on with people."

The mongoloid child, because of his physical uniqueness and his frequently severe retardation, places an enormous burden on the capacity of parents to love and care for a child at a time when they are least able to carry such a burden. In the early period of parenthood, just as in the early months of marriage, it is most difficult to accept the possibility of imperfection. It is during infancy that pediatricians, hospitals, and organizations such as the D. C. Clinic for Retarded Children can be of greatest help in giving parents support and time to reorganize their understanding of the child. If this is done, parents, at a later time, can make a reasonable and loving decision about the various possibilities available for the best care and development of a mongoloid child.

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Some Aspects of the Mentally Retarded Child and His Family in the Home

J. William Oberman, M.D.*

Approximately 90 per cent of all mentally retarded children are living at home.[1] While it is generally agreed that the presence of a severely handicapped child in the home creates many new difficulties and frequently exacerbates incompletely resolved interpersonal difficulties (actually to the point of sometimes destroying the family), a recent report by Saenger[2] gives striking evidence that this need not be true. Saenger studied 520 former pupils of the New York City Public School "trainable" classes (IQ's between 30 and 50) and found that two thirds were still to be found living in the community. He noted the surprising frequency with which the parents, regardless of background or station in life, accepted their retarded child. Ambivalent feelings were found in only 20 per cent of mothers and hidden or open rejection in only 10 per cent of mothers whose grown-up retarded child still remained at home. This continued acceptance of the retarded young adult was, as would be expected, related to the general emotional adjustment of the parents and was far less frequently found among parents whose child had been institutionalized. There was a high correlation between the existence of behavior problems and institutionalization; institutionalization was more likely to have occurred in children coming from broken families or those marked by low cohesion.

Holt[3] has noted that families from the upper social classes were not among those who were able to manage best when the mentally retarded child remained in the home; in general, most of these parents never overcame their frustration and disappointment at the child's inability to attain their ambitions for him. Instead, the ideal parents appeared to be those who, while sufficiently intelligent to appreciate the needs of the child and have some insight into his difficulties, did not have particularly great ambitions for him and so did not constantly show their disappointment. The presence of other normal children in the home made for much better adjustment, presumably because parents focused some of their hopes and desires upon these children; thus the defective child did not forever prey on their minds. It is Holt's feeling that some families are able to come to a deeper understanding of life through surmounting the burdens of having a retarded child. He feels that a family with a retarded child frequently needs superhuman effort to be able to lead a normal life in the community.

Holt's study further showed that severely retarded children who are

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living in the home do frequently present major problems of nursing care, the need for constant supervision, and attention at night. These added needs often result in exhaustion of either or both parents, falling-off of the father's work, adverse effects on normal siblings who are often unable to lead satisfactory lives of their own, inability of the mother ever to leave her child, and the parents never being able to go out on a holiday together. It is noteworthy that Holt's families live in Great Britain; speculation might arise that differing cultural patterns may explain discrepancies between this study and those by American authors.

Schipper[4] has noted that two thirds of 43 families in which a young mongoloid child was living in the home were able to integrate this child into the family without adversely changing their way of life. She noted that three quarters of the siblings were happy, well adjusted, and often more realistic than their parents in accepting the handicapped. Neighborhood relationships were disturbed in only about one quarter of the families; this was usually due to unacceptable behavior of the child or from the family's withdrawing from neighborhood contacts.

Difficulty in assessing a future intelligence potential of the retarded child cannot be overemphasized. Dunsdon and co-workers[5] gave intelligence tests to 44 mongoloid children, aged 8 to 15 years, selected from a group of 390 attending one clinic and thought to include those with the highest IQ's. Twenty of these children had IQ's over 45, and five had IQ's over 55. Although these children tended to do poorly in arithmetic, some children were only one to two years behind their estimated age level in reading ability. Eight of fourteen with IQ's over 45 were considered to be adjusting and learning satisfactorily in schools for the educably retarded.

Kelman[6] feels that the reaction of the family members to a mentally retarded child depends on such things as the type and severity of the disability, timing and circumstances under which the family was informed, nature of the family itself (housing, health, finances, family size, educational level), the family's religious, social and cultural tradition, personalities of the family members themselves and the nature of their interpersonal relations, and community attitudes toward the retarded child and his parents.

In an excellently thought out and well planned study, Farber[7] studied 88 families in which there was a retarded child with an IQ less than 50 living in the home. He noted that age, sex, and degree of dependence of the retarded child, in combination with the presence of normal brothers and sisters and the social status and religion of the family all determined the impact of the presence of the retarded child on such a family. He concludes that the parent can expect that a retarded boy, especially after the age of 9, will probably have a disruptive effect on marital relations; he feels the

parent can anticipate personality problems for the sister who is given many responsibilities for the child; and he believes that the parents can also expect a greater degree of helplessness of the retarded child to exert an adverse effect on the personality of his normal siblings.

Graliker and co-workers[8] have described the initial subjective reactions of a group of parents when given a diagnosis of mental retardation in their child. One third had questions as to the cause of mental retardation and why it happened to them, about half expressed feelings of rejection toward the child with associated shame or guilt, and 30 per cent worried about reactions of normal siblings, relatives and friends. Tarjan[1] has noted that in some situations the relationship between the retarded child and his mother becomes so mutually dependent that life apart is impossible. Lemkau[1] has characterized much of these feelings of shame or guilt to the traditional guilt people feel if something goes wrong in connection with the birth process. He feels that the defective child may be symbolic of all the bad things that the parent has done (or thinks he has done)—"the sins of the forefathers . . . ". Lemkau further has expressed the universal feeling that only by thorough diagnosis and ample opportunities for the parents to express their feelings can they hope to arrive at a healthy attitude toward their child. It is interesting that Holt[3] has noted that although many parents of retarded children did have these feelings of guilt, such was not necessarily so of parents of children who had postnatal causes of mental retardation (meningitis, encephalitis, etc.); he found these parents to be much better adjusted to the problem.

Throughout the foregoing discussion, there is a strong undercurrent leading away from the formerly held idea that the retarded child is something of a monster or visitation on the family, but rather a person with feelings and sensitivities, as well as an awareness of how society values him. In the family which has not been able to resolve its own feelings in respect to the retarded child, family integrity is threatened, and this is frequently reflected in the behavior problems and social difficulties sometimes observed in the retarded child. When, however, the family is able to accept the retarded child as a member of the family his integration into this setting adds to family strength.

The well known information gathered together by Bowlby and others[9] has called forth the widely accepted generalization that unless the young child receives adequate stimulation at appropriate times certain capacities will not develop. These findings have, of course, strong implications for a question of early institutionalization of the retarded child. It has long been accepted that a retarded child who has spent his early life in an intact family has many more abilities and is able to adapt much better to an institutional setting. Recently Centerwall and Centerwall[10] have com-

pared the physical and mental growth of mongoloid children put into foster placement soon after birth with those reared in their own homes until 2½ years of age or older; all had been in a state hospital for several years at the time of the comparison. These authors found that children reared in the home showed significantly better nutrition and growth and walked at a much earlier age. The differences in IQ, although small, were thought to be highly statistically significant. Slobody and Scanlan,[11] while admitting that a good many retardates will require institutionalization at some time in their life, feel that early placement is often ill advised and unnecessary and frequently causes serious emotional problems for both child and family. Farrell[12] has pointed out that the mother of a mongoloid child who has been institutionalized soon after birth may react with tremendous guilt when she sees that her lovable child who has been in an institution since birth is not the horrible monster that she had supposed.

SUMMARY AND CONCLUSIONS

The impact of a mentally retarded child on his family need not be a destructive one. Integration of a retarded child into the family is not only possible but highly desirable, both to facilitate the normal personality development of the child, and to help lessen the parents' almost inevitable feelings of guilt at having produced a child who is abnormal. As the seriously mentally retarded child grows older and larger, increasing difficulty may arise from his lack of adaptation to family life and his inability to fulfill his parents expectation of him. Factors determining whether the growing retarded child remains in the community or is institutionalized are many and complex. Should it become necessary to institutionalize the retarded child as he approaches adolescence, he has at least grown up in an environment that encouraged a healthy personality structure and the ability to make and maintain interpersonal relationships; his adjustment to institutional life will then be a much happier experience for the child, his family, and the institution.

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The Editor's Column

The Physician and the Retarded Child

This issue of the Clinical Proceedings helps bring into focus the extensive re-orientation of the past 10 years toward the problem of the mentally retarded child and his family. Unfortunately, most of this information has been printed in journals the average physician seldom reads. It seems obvious that with increasingly more effective means of controlling acute disease, a correspondingly greater portion of the physician's time will be spent in managing the chronic handicapping conditions of childhood; mental retardation is one of the chief members of this group. It would seem useful, therefore, to review current thinking on the relationship of the practicing physician to the family of the retarded child.

Kelman[1] has commented that physicians are often affected by negative community attitudes toward the retarded child and his family. This is particularly unfortunate, since the struggle that most parents experience in understanding their child and his handicap is greatly influenced by the nature of professional counsel that is available to them; in most cases, of course, the physician is the first one to confirm parental suspicion of mental retardation, and at this crucial time the manner in which the diagnosis is presented often has far-reaching consequences. Zwerling[2] has noted that the attitude and recommendations of the physician who first confirmed the

mental retardation, as well as the words he used, were indelibly imprinted on the minds of the parents; many parents commented on how devastating the experience had been. While some physicians were warm and understanding, many retreated behind a facade of scientific phrases which the parents had difficulty in understanding. Much of this was believed due to the fact that most physicians are poorly trained in understanding what mental retardation is and what having a mentally retarded child means to its parents. Lesser[3] believes that this pattern has recently been changing as physicians become more knowledgeable in this field. Cooke[3] has commented that it is not surprising that many physicians have adopted a negative attitude since in past years many authorities actually recommended that parents should not become emotionally involved with their defective child; in fact, these physicians were often told in medical school that it was better if the mother never even saw the child.

Koch and co-workers[4] have recently studied attitudes of 105 families toward previous medical care, diagnosis, and care and counseling concerning mental retardation. They noted that parents were satisfied only 47 per cent of the time when pediatricians handled the problem and only 55 per cent of the time when general practitioners were involved. Adverse comments included, "he was too rushed," "the examination was not thorough," "not interested in the child," "we weren't told anything," and "seemed hesitant to make a diagnosis." When the diagnosis was made, parents commented that the physician was "too blunt," "rushed us into placement," "was unfair in predicting the future," and "emphasized the effect on our other children."

Jenson[5] has described the three ways in which physicians talking to the parents most frequently increase their suffering: 1) "delay in defining the problem early in the patient's life"; 2)"encouragement of the parents by holding out false hopes which naturally result in disillusionment later"; and 3) "too much direct advice and/or urging adoption of a specific plan—too often institutionalization." Jenson notes that physicians frequently fail to remember that parents of a mentally handicapped child frequently have strong emotional ties to him; depending on the manner in which the diagnosis is presented, the parent may resist it quite strongly. Much disappointment and misunderstanding can be obviated by such simple procedures as the physician's providing ample time for thoroughly studying the child, using careful and explicit language in communicating his impressions to the parents, and above all *"respecting the right and the responsibility of the parents to determine disposition."*

Boggs[6] has expressed satisfaction with the increasing frequency with which articles have been appearing in professional journals urging a more individualized approach to the retarded child. She notes the trend toward

community clinics containing personnel from many disciplines and directed not only toward the diagnosis of mental retardation but toward follow-up guidance. In the 10 year period from 1949 to 1959, 70 clinics providing comprehensive and coordinated evaluation of the medical, psychological, social and educational factors operating in the mentally retarded individual have been organized throughout the country; the early ones were initiated at the urging of the parents group, The National Association for Retarded Children, the later ones set up through grants provided by the Children's Bureau.

Implicit in all the foregoing is that the views of the parents of the mentally retarded child, their desires for him and their potential difficulties in fitting him into the family group need to play a prominent part in determining further management of the child. Any plan of management, to be workable, must assuredly be individualized, practical in terms of available family and community resources, and in general realistic in taking into account the attitudes of all concerned parties.

Ideally, a comprehensive program for the retarded child should include: public school education if he is capable of adjusting to, and profiting from, a classroom experience; home instruction if he is unable to derive much benefit from a school experience; sheltered workshops, as he grows older, in order to assure that as a young retarded adult he is made as near a self-sufficient citizen of the community as possible; counseling and guidance for his family toward understanding and accepting his handicap and in planning realistic goals for him as well as the reduction of anxiety, guilt and hostility so frequently observed; supervision of the employment of the adult handicapped by mental retardation; direct communication between institutions and facilities in the community; and postinstitutional supervision, including counseling, guidance, and support in employment.[7]

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Editorial

"What He Is"—A Reflection

Several articles in this issue abstract advice and opinions from multiple sources on the responsibility of the physician, the family, and the community to the retarded child. Over and over, in varying ways and with varying intensity, writers indicate: the physician should be interested as diagnostician and counsellor; the parents must learn the limitations and capabilities of the retarded child, must understand him; the community must take steps to provide diagnostic, counselling, placement and institutional services; all must recognize the retarded child for "what he is."

On reflection, one is impressed with the frigidity of these conclusions unless, at the same time, there is consideration of the "why." *Why* should we bother about the retarded child? In a positive rather than a negative sense, what is our real concept of "what he is?"

One point of view is this: Regardless of the shell or the form or the performance in worldly endeavors, the retarded child is still, in essence, a human soul. The retarded child is then a child of God and a spiritual likeness of God whose destiny is to return to God. From this basis—or from a consideration that a human being possesses human "dignity" regardless of human form—there can flow at once consolation for worldly grief at the imperfection of the "shell" and motivation for loving, intelligent, and sometimes selfless care for the retarded child. In theory, this point of view makes the only real sense in answer to the question of "why." In practice it is the best impetus for further study and improved care of the retarded child or, for that matter, any crippled or handicapped child.

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